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Hearing on Assisted Suicide Funding Restriction Act of 1997
House Commerce Subcommittee on Health and Environment
March 6, 1997

I am testifying today in support of the Assisted Suicide Funding Restriction Act of 1997. As a physician involved in hospice care, and as a medical director and palliative medicine consultant I have cared for dying patients for nearly 20 years. During fourteen years of this time; I also practiced emergency medicine in a mixture of urban and rural settings. Additionally, during the past several years I have traveled throughout our country, teaching and consulting with hospice programs and medical centers that are striving to improve care for the dying. I have seen some of the best examples of care and some of the worst. These experiences have provided the perspective from which I speak today.

In passing Measure 16 by a narrow margin the voters in Oregon expressed their belief that legalizing physician-assisted suicide represents an important extension of personal freedoms. I respectfully disagree. Against the backdrop of the failure of many doctors and health care institutions to respect the treatment preferences of patients, amidst the widespread documented critical deficiencies in pain and symptom management and the current inability of the public sector to adequately help families meet the basic needs of people as they die I believe that legalized physician-assisted suicide represents, instead, regressive social policy and a dangerous diminution of clinical standards.

Assisted suicide and the crisis in end of life care

There is a crisis in care for the dying, but this is not the way to address it. While respecting the right of the citizens of Oregon to make laws that affect themselves, it is imperative that the Federal government avoid complicity with and tacit support for assisted suicide by

restricting payment for such **services** and by exempting **physician-assisted** suicide from provisions of the Patient Self-Determination Act. In absence of the Assisted Suicide Funding Restriction Act of 1997, Federal tax dollars would be conscripted and, without their consent, American taxpayers would become **complicit** in these actions.

Whenever a serious social crisis is identified, it is an essential role of government to attempt to correct it. While purporting to address the crisis in care for the dying, the authors of Measure 16 have presented a quick, technological **fix** that intentionally exempts entire categories of dying persons and leaves the causes of suffering unaddressed. While the **intention** is admirable, the strategy chosen is flawed.

Supporters of legalizing physician-assisted suicide contend that **it** is a right of dying persons yet, through so-called safeguards deny this right to dying persons who are developmentally handicapped or recently demented or mentally ill. or are children. Their suffering is unaddressed **Once** again, their lives **undervalued**.

If pushed to respond to these concerns, supporters of Measure 16 usually acknowledge that it is only a first step and that once it can be proven workable, and when society is ready, **the right to physician-assisted** suicide can be broadened to other categories of patients. This, of course, is exactly what people with **disabilities** and a growing number of HIV positive **people** fear.

At times **it** is asserted that physician-assisted suicide is a purely personal and **private act** and, thus: that those of us in society and in the medical profession who object **to** the practice need not be **involved**, but should leave others to do what they wish. While suicide may in some circumstances be purely private, physicians, as professionals, act as agents for the larger **society**. Physicians receive **training** from society's highly subsidized medical education programs, they are licensed by boards of medicine and **certified** by specialty boards duly recognized by **accrediting** bodies. Physicians are reimbursed by society for the specialized work **that** they do. In return, we are expected to act within **high** professional standards of behavior toward **patients** who are in an inherently vulnerable position. **Parenthetically**, this is why, even in situations of mutual consent, society strenuously proscribes physicians from having sexual relations with patients.

In fact, the social construction of rights must be balanced with the concept of social responsibilities. In this regard it seems poignantly ironic that two Federal courts have recognized a Constitutional **right** to assisted suicide just three years after Congress and the nation decided there was no right to health care.

As **assisted suicide** becomes legal in Oregon, across the country health care services for the poor have been restricted. Programs through which people would have been taught breast self-examination and undergone pap smears and colon cancer screening have been curtailed. In inner cities and poor rural areas, many clinics and county **hospitals** where early detection and treatment of cancer and HIV disease might have saved lives have been **closed or have cut back** on services. Today however, **when a patient's cancer or HIV** disease is far advanced and, perhaps coincidentally, at a time when their care is most expensive, we are poised to **extend** a new right to a preemptive death.

The "slippery slope" about which opponents of assisted-suicide worry is not merely a **projection of what may happen** in the future. The **poor**, advanced elderly and socially disadvantaged have already slid to a lower tier of medical care and basic human support. In general, nursing homes in this country are not places where any of us wish to live, nor wish our loved ones to end up. With few exceptions, **nursing** homes for the care of the indigent are abysmal. While corporations continue to make huge profits, nursing homes where as many as 25% of Americans die remain woefully understaffed Attendant positions within the **nursing** home and home health industry -- **often** the people who most directly care for our grandparents, **parents**, siblings and spouses in their **frailty** and physical dependence -- are filled by underpaid, **entry** level workers who are currently accorded little respect within either the **medical** and human resource **professions**.

Surveys of patients and the general public reveal that pain, fear of future pain and the sense of being a burden to one's family are Important causes for people to support and to seek assisted suicide

It is pertinent that studies document that being poor or speaking a language other than English is a significant risk factor for inadequate pain management.' ² In a sentinel study of cancer pain management in 54 university-affiliated clinics across the country 42% of

patients were found to have been given inadequate pain medication on the basis of World Health Organization standards of analgesia. More disturbing that figure rose to 59% of patients undertreated in those centers that cared for a mainly black or Hispanic population.' Another, independent high risk factor for undertreatment of pain in the study was being over 70 years of age.

In this context reports suggesting that in some areas as many as 25% of persons with advanced HIV disease are dying by doctor-assisted suicide are of serious concern. Without question, because of their sexual preference or use of IV drugs, persons with HIV disease are among the most ostracized, disadvantaged groups in our country. They are among those who are least likely to have traditional families to welcome them home and care for them. Despite wonderful examples of support within the gay community, social isolation and abandonment remain all-too-common. HIV infected people are given clear messages by society that their illness is their own fault and that their lives are not valued, that they are unwanted. Many HIV positive individuals are finding it hard, or impossible, to pay for life-saving combinations of medications. Meanwhile, clinical studies reveal that the pain and other symptoms causing physical distress in HIV disease are also undertreated.⁷

It may not be many years after Measure 16 -- or a similar measure elsewhere -- is implemented that a watchdog agency documents that this new social service is being used disproportionately by persons who are gay, by persons of color or by the poor. Perhaps then there will be outrage. More frighteningly still, perhaps not.

In fact, care for the dying, including such basic issues as the control of pain and the management of physical discomfort has been inadequately taught and inadequately practiced within even our most prestigious medical institutions.^{3,4,5,6} The barriers to effective symptom management are discernible and approachable. Corrective action is required. The sanctioning of their preemptive death would tacitly support the lamentable status quo.

When a person's options have been narrowed to suffering or suicide, the choice of suicide may be rational, but it is all the more tragic.

Building a brighter future

The response of a caring society must be to create other options. We have the opportunity as a nation of building higher ground above this increasingly divisive debate. The truth about dying is that it does not have to be horrifying.

America can **realistically** achieve, and afford to develop a system of care that ensures that no one need die in physical agony and no one need die alone. We have within our professions and **within** our communities the know how to care for people in ways that ensure relative comfort and allow them to feel wanted, worthy and dignified despite their terminal frailty and physical dependence. All we need now is the commitment to do it.

As large as the problem is, unlike global warming or urban violence, this particular crisis can be resolved within a short time; perhaps within a decade, if we are determined to do so. In responding to causes of suffering among the dying, Congress can construct alternatives that meet the needs of all Americans as **they** die.

Hospice programs across the country have demonstrated that comprehensive person and family centered care is effective, practical and affordable. The nation's best hospices and a number of innovative community-based programs of support of personal and family support **provide** important examples of what works, upon **which** we can build.

Dying patients **are**, by **definition**, among the very sickest patients in the health care system. When practiced appropriately, hospice care is often a form of "intensive care."

Hospice care represents a genuine team approach to the care of the patient and family and the management of symptoms and suffering. In **addition** to experienced hospice nursing evaluation, **when** symptoms are not readily controlled, the active involvement of a physician with special interest and expertise in palliative medicine is essential.

Consultation with specialists in medical oncology, radiation oncology, neurology, surgery and **anesthesiology**, psychology and psychiatry should be available and utilized as necessary. The care team must include members with experience and special interest from **disciplines** of pharmacy, social work, chaplaincy as well as physical, occupational and other allied health therapies. Trained and supervised volunteers from the community can provide

support, companionship and help bear witness to the unique stories, sorrows and triumphs of the person departing.

The statement "some physical pain associated with dying can not be controlled" is often repeated and widely believed. However, it is the experience of hospice physicians that physical suffering associated with dying can always be alleviated. Achieving relative comfort among the dying is not always easy. At times it requires enormous effort and intensive palliative interventions. It is, however, always possible.

While relief from physical distress is the first priority of end of life care, it is not the ultimate goal. Beyond morphine and skilled medical care, it is possible to attend the dying in ways that honor and even celebrate their lives. People can be sat with, in quiet conversation or in silence. They can be sung to and their skin gently oiled. What is valued by the person and family, they can be prayed with,

Truly excellent care embodies goals that extend beyond relief of suffering and seeks to preserve the potential for persons and their families to grow, inwardly and together. Care that is this tender and loving is exemplified by our country's best hospice programs. It has been proven to be effective and affordable. In responding to the crisis in care for the dying, Congress should settle for no less, whether people are being treated at home, in nursing homes or in hospitals.

Today fewer than one in five Americans are fortunate enough to experience the sort of comprehensive end of life care that hospice provides. Outmoded habits of medical practice and outdated Medicare, Medicaid and insurance regulations effectively exclude most patients dying of advanced heart or lung disease, as well as those with Alzheimer's or AIDS, from receiving this intensive level of medical and tender human care. These exclusions persist despite studies that suggest that hospice is as much a third less expensive than medical care in its absence.

As important as it is in passing the Assisted Suicide Funding Restriction Act of 1997, Congress will only have stated what it is against. Congress has the challenge of stating what it is for and, in so doing, the opportunity to address and effectively eliminate many of

the roots of the crisis

Congressional action should be considered in the following areas

- Adoption of the Medicare Hospice Benefits Amendments of 1997. This bill would correct some of the current fiscal and bureaucratic restrictions to hospice care, improving access among people with non-cancer diagnoses, people living in nursing homes and people residing in rural areas.
- Establishing of a requirement for Federally subsidized medical and nursing schools to incorporate basic symptom management and care of the person and family confronting life-limiting illness within core curriculum of training and establish basic competency in these areas among the criteria for graduation.
- Requiring that hospice, or similar models of comprehensive end of life care, become a basic element of service within Federal systems of health care (such as the Veterans Administration, the Indian Health Service, CHAMPUS) as well as under Medicare and Medicaid payment to hospitals, nursing homes and health maintenance organizations.
- Specifying that HMO's must offer hospice services as an integral component of care.
- Instituting a requirement for physicians who practice within Federal health care systems to document competence in basic symptom management
- Directing the National Institutes of Health to emphasize palliative medicine among its funding and research priorities. In this regard there is an urgent need to develop clinical outcome measures that are pertinent to end of life care (such as quality of life and quality of family experience measures) as basic tools that can advance clinical research in palliative medicine.

- **Requiring** nursing homes to Increase levels of staffing of nurses and aides as well as requirements for training and certification of aide level personnel.

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As a nation, we are right to finally confront the stark reality of needless suffering among the dying. We can **provide** solace and preserve dignity and human potential through the **very** end of **life**. Instead of arguing whether assisted suicide should be legal or illegal, let's do what is needed to make it irrelevant,

As **President** of the American Academy of Hospice and **Palliative** Medicine, I offer the collective **resources** of our membership to the Subcommittee and your colleagues in these and **related** efforts, I thank you for the opportunity to contribute to your deliberations today.

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